

**Grandparents & Other Relatives Raising Children: Characteristics, Needs,
Best Practices, & Implications for the Aging Network**

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EXECUTIVE SUMMARY

Grandparents and other relatives raising children were, until recently, a largely forgotten part of America's caregiver population. A more than 50% increase from 1990-98 in the number of children being raised solely by relatives (Casper and Bryson, 1998), however, along with evidence of their often substantial health and social problems, have helped focus needed attention on this growing caregiver group.

Substance abuse, the rise in single headed households, HIV/AIDS, sharp increases in female incarceration, and policy changes favoring relative placement of children over non relative foster care are among the reasons for the dramatic growth in grandparent caregiving (Burnette, 1997; Minkler, 1999).

More than one in ten American grandparents or other relatives raise a grandchild for at least 6 months at some point in their lives, and typically for far longer periods of time. For almost three quarters of these grandparents, caregiving begins when the child is an infant or preschooler (Fuller-Thomson et. al, 1997). By the late 1990's, 5.4 million children were living in grandparent or other relative-headed households, and in almost 40% of these cases, neither of the children's parents were present (Casper and Bryson, 1998). Although the typical relative caregiver is a married white woman living modestly but above the poverty line, single women, African Americans and the poor have greatly increased likelihood of taking on this role (Chalfie, 1994; Fuller-Thomson et. al, 1997; Harden et. al, 1997).

While grandparent and other relative caregivers exhibit many strengths, they also face numerous challenges, and are at significantly increased risk for depression, functional limitations and financial difficulties. More than one in four relative headed households are poor (Casper and Bryson, 1998), and among grandmother caregivers, close to a third suffer depression, and over half have at least one limitation in an activity of daily living (Fuller-Thomson and Minkler, 2000). Relative caregivers often also face a plethora of challenges in accessing needed health and other services for the children in their care. In 1996, for example, one in three children living in grandparent-headed households were without health insurance (Casper and Bryson, 1998). For the great

majority of caregivers who do not have legal custody or guardianship of the children they are raising, such problems are particularly acute.

In light of both the growth of the relative caregiver population and the many challenges and unmet needs of intergenerational households headed by grandparents, the decision to include such caregivers within the National Family Caregiver Support Program (NFCSP) is both timely and important. States may use up to 10% of their total NFCSP funds to support programs and services for relative caregivers aged 60+ and the children in their care, allocating funds to the Area Agencies on Aging (AAAs) which in turn either provide services directly or contract out for their provision (USDHHS/AoA, 2001).

Many AAAs and state units on aging had begun responding to the special needs of older relative caregivers well before the creation of the NFCSP. Often beginning with seed grants from the Brookdale Foundation Group's Relatives as Parents Program (RAPP), these interventions typically involved the creation of grandparent support groups, but also have included a variety of other programs and services such as counseling, resource centers, written guides and newsletters, legal assistance, respite and child focused activities. Both within and outside the aging network, a number of comprehensive programs also have been developed for relative caregivers and their families, which include interventions on multiple levels to assist and support such families.

Several national resources are available to help members of the aging network in their efforts to develop or expand programs and services for older relative caregivers through the NFCSP. Key among these are the above mentioned Brookdale Foundation Group's RAPP program; Generations United, the only national membership organization devoted exclusively to promoting intergenerational strategies, programs and policies; and AARP's Grandparent Information Center (GIC), which maintains a data base of over 800 support groups and other programs for relative caregivers in all 50 states. Generations United's A Guide to the NFCSP and its inclusion of grandparents and other relatives raising children (Beltran, 2001), and the data bases of programs available through the Brookdale Foundation Group and AARP's Grandparent Information Center

(GIC) represent particularly good sources of information for AAA's and state units on aging in this regard.

"Best practices" for meeting the needs of relative caregivers and their families can be found in relation to each of the five areas of support designated by the NFCSP.

Information to caregivers about available services is provided through the printed written guides, web sites, and other resources made available through different AAAs and state units on aging. Assistance in gaining access to services includes the provision of kinship care "navigators" to help negotiate the legal system and access benefits, as well as the conducting of comprehensive family assessments with subsequent referrals to appropriate programs and services. Individual counseling, the organization of support groups, and training of caregivers are the areas in which the aging network has probably been most active to date, with a particularly heavy emphasis on the organizing of support groups. When such groups have been initiated in collaboration with other agencies, they sometimes have been able to provide childcare and other ancillary services which can help overcome major barriers to participation. Respite services for caregivers include both center-based models and in-home respite, and in this regard too, creative partnerships with organizations such the YMCA have been developed. Finally, supplemental services encompass a broad range of possibilities thanks in part to the intentional breath and flexibility written into the NFCSP particularly where this category of services provision is concerned. Supplemental services have included, for example, addressing the special mental health and educational needs of children in the care of relatives; nurturing leadership among grandparent caregivers; providing toll free hot lines for kinship caregivers; and organizing statewide trainings and conferences on kinship care for both caregivers and providers.

The many often interrelated needs of relative caregivers and their families underscore the importance of developing interventions that are comprehensive and multi-level in focus. The California-based Edgewood Center's Kinship Support Program; the GrandCare Program for Grandparents and Other Relatives Raising Children in Charlotte, North Carolina; and Boston's GrandFamilies House represent three outstanding examples

of comprehensive programs with which members of the aging network may wish to become familiar.

Several principles are useful in helping to guide the work of state units on aging and AAAs as they seek to develop or expand programs to assist older grandparent caregivers with the aid of the NFCSP. These include the need to:

- “Start where the people are” before deciding on a new program or activity, so that the voices and concerns of relative caregivers help ensure that the services developed represent those of greatest felt need.
- Identify and address the special cultural, linguistic and other needs and concerns of diverse groups or relative caregivers.
- Search out and develop creative partnerships, which can greatly increase the resource base, visibility and effectiveness of NFCSP efforts.
- Think broadly and creatively, taking advantage of the deliberately broad and non-specific language of the NFCSP, especially in the area of “supplementary services.”
- Recognize and build on the strengths of grandparent and other relative caregivers, by providing them opportunities for leadership training, etc. and
- Maintain open communication with organizations that can advocate for policy change. By providing stories and other documentation, members of the aging network can help organizations like AARP, Generations United, the Children’s Defense Fund, and the Child Welfare League of America in their efforts to promote legislation that supports relative caregivers and their families.

The NFCSP provides a wonderful opportunity for the aging network in its efforts to address the needs and build on the strengths of older grandparent and other relative

caregivers and their families. Together with policy changes that support such families, the Program can make a real difference in the lives of this rapidly growing, vitally important, and critically underserved group of caregivers.

Grandparents & Other Relatives Raising Children: Characteristics, Needs, and Implications for the Aging Network

INTRODUCTION

The last two decades have witnessed a dramatic increase in the number of children living with, and often in the care of, grandparents or other relatives. Between 1990 and 1998, the number of children being raised solely by grandparents or other relatives grew by over 50% and by the late 1990's, 5.4 million children live in homes headed by grandparents or other relatives. For almost 40% of these children, neither parent was present in the home (Casper and Bryson, 1998).

Grandparents and other relatives raising children often face many of the problems associated with other forms of caregiving and including depression, functional health limitations, financial difficulties and social isolation. In addition, however, they are raising many of the nation's most vulnerable children. It is therefore both timely and important that states have been authorized to use up to 10% of their National Family Caregiver Support Program (NFCSP) funds to assist older relative caregivers.¹ The Program's stipulation that priority be given to caregivers in the greatest financial and social need also is important, since as indicated below, a sizable proportion of relative caregivers live at or below the poverty line, and many suffer social isolation, depression and other problems. Finally, the fact that the 10% figure applies statewide (USDHHS/AoA, 2001) should be seen as offering each state considerable freedom in allocating funds in ways that best serve the greatest number of relative caregivers in need. AAAs serving low income inner city communities where relative caregiving is known to

¹ Under the reauthorization of the Older Americans Act which created the NFCSP, states are allowed to use up to 10% of their total Federal and non-Federal share of NFCSP funds to provide support services to older relative caregivers. Caregivers may be grandparents, step-grandparents, or relatives by blood or marriage of children aged 18 or younger with whom they are living and for whom they serve as primary caregiver. Such caregivers must be aged 60 or above, and may either have legal custody or guardianship of the children in their care, or be raising them informally.

be disproportionately concentrated (Burnette, 1997) thus could be allocated a greater share of funds with which to address this issue.

Toward the end of aiding the aging network in its efforts to develop and expand creative approaches to meeting the needs of older relative caregivers, this monograph provides a profile of American grandparents raising grandchildren,² and highlights the major challenges and problems confronting such caregivers and their families. An overview of the broad range of supportive community based programs and services for such families then is presented, along with a look at the major national resources available to members of the aging network concerned with developing programs. The monograph then presents a selection of “best practices” on the state and local levels, within the context of the five categories of assistance delineated by the NFCSP. A particular emphasis will be placed on sample programs that have been developed by state units on aging and Area Agencies on Aging (AAAs), and the creative partnerships forged to create such programs. Several examples of comprehensive programs which combine services and activities in most or all of the five support categories utilized by the NFCSP also are presented.

The paper concludes with implications for the aging network as it attempts to better address the needs of the growing number of older relatives raising children in the United States. Helpful resources on relative caregiving, as well as web sites and other contact information for the best practices and other programs cited in this monograph, are included as an appendix.

A PROFILE OF AMERICAN RELATIVE CAREGIVERS

Serving as the primary caregiver to one's grandchildren is not an uncommon experience: More than one in ten grandparents (10.9%) at some point raise a grandchild for at least six months, and usually for far longer periods of time. The median age of

² In programs, policy and research documents, the terms “grandparent caregiver” and “grandparents raising grandchildren” often are used as generic references which include great grandparents, aunts and other relatives raising children, in addition to grandparents. In keeping with this convention, the term “grandparent” sometimes is used in this paper in reference to the broader category of relative caregivers.

grandparent caregivers is 59.3 and over half are aged 60 and above (Fuller-Thomson et. al, 1997).

The typical grandparent raising a grandchild is a white married woman living modestly but above the poverty line. Nationally, slightly more than half of grandparent caregivers are married (54%) more than three quarters (77%) are women, and 62% are non Hispanic white (Fuller Thomson et al, 1997). However, being single, living in poverty, and being an African American substantially increase the odds of becoming a caregiver for one's grandchildren (Casper and Bryson, 1998; Chalfie, 1994; Fuller-Thomson et. al; Harden et. al, 1997). African American children, for example, are four to five times more likely than non Hispanic white children to be living in "kinship care" households --those in which children have been formally placed with their grandparents or other relatives (Harden et. al, 1997)--a fact reflecting both current socioeconomic realities and a long history of caregiving across generations in Black families (Burton & Dilworth Anderson, 1991).

Although not as prevalent as in African American families, grandparent caregiving also appears more common among Latinos, with 6.5% of Hispanic children (compared to 4.1% of whites and 13.5% of African Americans) living with grandparents or other relatives (Lugalia, 1998). While the duration of intergenerational residence varies by race, class, region, and other factors, almost 3/4ths (72%) of children who come into the care of a grandparent do so when they are infants or preschoolers (Fuller-Thomson et. al, 1997, and hence demanding a particularly intensive degree of care.

REASONS FOR THE INCREASE IN RELATIVE CAREGIVING

Part of the increase in kinship care beginning in the 1980's is attributed to legal mandates and changes in child welfare reimbursement policies and practices that encouraged placement with relatives over non relative foster care (Berrick and Needell, 1999). Kinship care is the fastest growing out- of- home placement funded by child welfare agencies and in many large urban areas, half of the children in out-of –home placements are in the care of relatives. Federal and state laws and policies promoting formal kinship care, however, care do not explain the sizable concomitant growth in the number of children who informally have been "going to Grandma's" --to stay (Cox,

1999). Indeed, informal estimates suggest that for every one grandchild in the formal foster care system, another six are informally being raised by relatives (Harden et. al, 1997; Needell, 2001).

Key among the social factors contributing to this increase is substance abuse, and particularly the cocaine epidemic (Burnette, 1997; Feig, 1990). The facts that an estimated 15% of women aged 15-44 are substance abusers, and that almost 40% of these women have children living with them (NIDA, 1997), suggest that drug and alcohol abuse are likely to remain important contributing factors.

Divorce, teen pregnancy, and the rapid growth in single parent households also are major factors responsible for the rise in intergenerational households headed by grandparents. Such trends have contributed to the dramatic drop in the number of children living in two parent households, (from over 86% in 1950 to about 70% by the mid 1990's)--a factor which appears to increase the likelihood of children entering relative care (Harden et al., 1997).

The HIV/AIDS epidemic is another growing contributor to the phenomenon of grandparent caregiving. The leading cause of death among African Americans aged 25-44, HIV/AIDS had claimed the lives of the mothers of an estimated 125,000 to 150,000 American children and youth by the year 2000. Although custody data are limited, available information suggests that grandmothers typically are the sole or primary caregivers to children whose primary parent is living with, or has died as a result of AIDS (Joslin and Harrison, 1998).

Grandparents also are primary caregivers to well over half of the children of imprisoned mothers in the U.S. Dramatic increases in the number of incarcerated women, which grew six fold over the last decade and a half, (Dept. of Justice, 1997) suggest that this trend will likely continue to contribute to the growth of intergenerational households headed by grandparents.

Finally, it should be stressed that most all of the factors discussed above are tied in fundamental ways to the continued problem of poverty in our nation, which itself remains a significant vulnerability factor for grandparent caregiving (Burnette, 1997; Minkler, 1999).

RELATIVE HEADED HOUSEHOLDS: SPECIAL CHALLENGES

Intergenerational households headed by grandparents exhibit many strengths, with grandparents who assume caregiving often doing so willingly and with relief that they can "be there for the grandchildren." The children in such families also frequently appear to be doing well. A national study by Solomon and Marx (1995) thus revealed that both in terms of health and school adjustment, children raised solely by grandparents, while not doing as well as those in two parent households, fared better than those in families with one biological parent present. At the same time, grandparent headed families also face a number of problems and challenges:

Health and health care access

High rates of depression, poor self rated health, and/or the frequent presence of multiple chronic health problems have been reported in both national and smaller scale studies of grandparents raising grandchildren. (Burton, 1992; Minkler and Roe, 1993; Burnette, in press; Dowdell, 1995; Minkler et al, 1997). Such problems appear particularly prevalent among caregiving grandmothers. One national study thus found that thus found that 32% of caregiving grandmothers met the clinical criteria for depression, compared to 19% of non caregiving grandmothers. Similarly, grandmothers raising grandchildren were significantly more likely to have limitations in Activities of Daily Living (ADL's) such as caring for personal needs, climbing a flight of stairs, or walking six blocks, with fully 56% reporting at least one ADL limitation (Fuller-Thomson and Minkler, 2000).

As noted above, children in relative headed households may have better health overall than children living with a single parent (Solomon and Marx, 1995). But significant health and related problems have been observed, particularly among those children who came into the grandparents' care having been prenatally exposed to drugs or alcohol, and/or having suffered parental abuse or neglect. High rates of asthma and other respiratory problems, weakened immune systems, poor eating and sleeping patterns, physical disabilities and attention deficit hyperactivity disorder (ADHD) are among the problems experienced, and which in turn may take a toll on the caregiver's physical and mental health (Dowdell, 1995; Minkler and Roe, 1996; Shore and Hayslip, 1994).

Several studies have documented the tendency for caregivers to delay or fail to seek formal help for themselves, particularly with mental or emotional health problems (Burnette, 1999 a & b; Minkler et. al, 1992; Shore and Hayslip, 1994). Accessing needed health services for the grandchildren in their care also may be impeded by lack of insurance coverage. Many insurance companies refuse to allow grandparents to include grandchildren as dependents on their insurance policies unless the children are in legal custody of the policy holder (Cohon, 2001). In 1996, one in three children in grandparent headed households was without health insurance, compared to one in seven in the overall child population (Casper and Bryson, 1998).

Social isolation and alienation

Decreased socialization with friends and/or family, and an inability to continue participation in senior centers and church activities as a consequence of caregiving responsibilities has been widely reported among caregiving grandparents (Burton, 1992; Jendrek, 1994; Minkler and Roe, 1993; Shore and Hayslip, 1994). Substantial declines in marital satisfaction also have been noted (Jendrek, 1994). Intergenerational households formed as a result of parental AIDS or drug addiction may experience special feelings of alienation (Burnette, 1997; Joslin and Harrison, 1999; Minkler and Roe, 1993), with some African American and Hispanic grandparents reporting that the failure of their communities, and particularly their churches, to openly acknowledge the extent of AIDS or crack use in their midst have contributed to the sense of isolation and shame experienced.

Financial vulnerability and the inadequacy of public assistance

As noted earlier, grandparent headed households have substantially higher poverty rates than other family units, with 27%, or over one in four, living below the poverty line. Becoming the primary caregiver for one's grandchildren often further exacerbates already difficult economic circumstances. For older working relatives, the assumption of caregiving frequently means quitting a job, cutting back on hours, or making other job related sacrifices that may put their own future economic well being in jeopardy. Retired or non employed caregivers also frequently suffer financially, and sometimes report spending their life savings, selling the car, or cashing in life insurance to cope financially with the new role (Minkler and Roe, 1993).

Prior to its repeal under welfare reform in 1996, Aid to Families with Dependent Children (AFDC) was the primary source of public assistance to intergenerational households headed by grandparents, providing both cash assistance and automatic eligibility for Medicaid and other benefits. Under the replacement program, Temporary Assistance to Needy Family (TANF), work requirements, time limits and other restrictions may constrain a low income grandparent's ability to receive benefits for her family. TANF "child only" grants remain an important, albeit often inadequate, source of support for the children in many grandparent headed families. Data are not yet available, however, on the number of such households that have suffered financial hardship as a consequence of welfare reform (See Mullen and Einhorn, 2000 for a detailed discussion of state level welfare reform/TANF choices and grandparent headed households).

For grandparents who enter formal kinship care arrangements, foster care payments are available, typically at substantially higher rates than TANF. Finally, in approximately 20 states, stipended guardianships recently have become available through which relative who were in the formal foster care system may exit the system and still receive financial support, typically at a rate higher than TANF but lower than foster care rates. Such new alternatives may be critical to an older relative's ability to cope with the added and often sudden financial demands that come with rearing grandchildren. Yet many grandparent headed households still fail to receive the support for which they are eligible and/or experience considerable delay, red tape, and other difficulties in trying to access needed financial assistance (Burnette, 1997; Generations United, 1998).

Legal issues

Grandparent and other relative caregivers often face a bewildering set of legal issues. Legal authority over the children in their care can take several forms including adoption, custody or guardianship. While such arrangements are helpful in enabling grandparents to access needed services and supports for the children in their care, the legal proceedings involved can be costly, time consuming, and emotionally wrenching. Hopes about the eventual reunification of children with their parents, and fear of antagonizing an adult

child by pursuing legal proceedings, also make many caregivers reluctant to take steps formalizing custody or guardianship (Generations United, 2001; Minkler, 1999).

Although informal caregiving frequently is preferred in such cases, it too is problematic, as caregivers without legal sanction may face difficulties in their dealings with schools, health facilities and other agencies that may require proof of legal authority as a condition of providing services. In the face of this Catch 22, a growing number of states have developed creative options to allow informal caregivers to more easily access needed benefits for the children in their care. “Consent legislation” thus enables parents to transfer authority in particular areas (e.g., involving medical assistance or school enrollment) to caregivers, while standby guardianship, first developed in New York in response to the HIV/AIDS epidemic, allows terminally ill parents to designate a guardian effective at the time when the parent dies or becomes too incapacitated to provide care. Far more movement is needed, however, in the direction of creatively addressing the myriad legal challenges faced by relative caregivers.

Housing

Access to adequate and affordable housing is a major concern for many grandparents and other older relatives who are raising grandchildren. Low income caregivers in particular may be severely limited in their ability to purchase adequate housing, and state level public housing authorities lack policies that address the special needs of such families. Grandparents in senior housing can be evicted for taking in grandchildren, while in other types of public housing, legal guardianship papers may be required to prevent eviction. Finally, even grandparents who are allowed to have their grandchildren live with them often report that space is an issue, and particularly having an adequate number of bedrooms. Although some creative approaches to meeting the needs of grandparent headed families have been developed in selected areas (see Grandfamilies House below), broader policy changes are needed. As articulated by Generations United in its Public Policy Agenda for the 107th Congress, such changes should include the creation of a national demonstration project to address the needs of such families. Training of Housing and Urban Development (HUD) personnel in the special needs of relative headed households, and increasing the flexibility of existing housing programs vis a vis space

requirements etc. so that they better accommodate the needs of these families (Generations United, 2001).

In sum, and although grandparents raising grandchildren experience many rewards, the challenges and difficulties they face should not be underestimated. The decision to earmark up to 10% of NFCSP funds to provide services to relative caregivers stands as an important example of the growing recognition of this often neglected caregiving population and its special needs and challenges. In the next section, the broad range of supportive services developed to assist such families is described, as an introduction to the varied ways in which the aging network can –and has already begun to-- address the special needs of grandparent and other relative caregivers and their families.

THE RANGE OF SUPPORTIVE INTERVENTIONS FOR GRANDPARENT & OTHER RELATIVE CAREGIVERS AND THEIR FAMILIES

The last fifteen years have witnessed the growth of a wide range of supportive interventions for relative caregivers and their families. By far the most common are support groups, which run the gamut from informal weekly or monthly meetings in a grandparent's home to well funded therapeutic support groups providing child care, transportation, counseling, and a host of special programs and activities (Roe and Minkler, 1998). AARP's Grandparent Information Center described below currently lists approximately 800 support groups for relative caregivers. Such groups can have measurable effects on participants' self esteem and well being (Burnette, 1998). They also can provide an avenue through which many caregivers can "give back" to their communities, by serving as co-facilitators and helping others learn from their experiences. Without external support, however, most such groups come and go as interest and resources vary over time (Roe and Minkler, 1998).

For relative caregivers in rural areas and others either unable to access or uncomfortable with the idea of support groups, special "warm lines" offering emotional and informational support by telephone, and Internet chat rooms and resource-oriented Web sites for relative caregivers also can be critical. On a larger scale, resource centers

on the local through the national levels have proven valuable sources of information and referrals for relative caregivers, service providers, educators and other constituents. Local resource centers serve as clearinghouses for grandparents and professionals in need of assistance or referrals, with their larger counterparts offering a full range of integrated resources and services that can assist individuals as well as social service agencies through conferences, town hall meetings, policy forums and advocacy. Some of these resource centers, key among them AARP's Grandparent Information Center (GIC) described below, are able to reach through multiple levels of the social system and stimulate policy and service coordination in support of grandparents raising grandchildren, as well as providing one-on-one information and referral (Roe and Minkler, 1998). A number of AAAs and state units on aging have already developed resource centers on relative caregivers and their families, often with the help of the GIC and the Brookdale Foundation Group's RAPP (Relatives as Second Parents) program described below. And in Michigan, the state unit on aging indeed now asks that AAA's use 10% of the funds they receive from the State for relative caregiver activities to develop a grandparent caregiver resource center (Sainer, 2001).

Comprehensive programs for relative caregivers and their families also have been developed, some of which have targeted households facing particular challenges. Programs for grandparents raising the children of imprisoned mothers, for example, have been developed in Boston, Atlanta, and San Francisco, offering legal services, transportation for visitations, and respite care, in addition to support groups and other activities (Dressell & Barnhill, 1994; Minkler and Roe, 1993).

Although programmatic interventions to assist relative caregivers and their families play a critical role on the individual and family levels, broader policy changes also are needed to help address the multiple needs of these intergenerational households. In part toward the end of helping to support needed policy changes, a number of local, state and national relative caregiver coalitions have been established. Groups such as the Wisconsin based National Coalition of Grandparents (NCOG), and the California based Grandparents as Parents (GAP) regularly receive calls from legislators and the mass media, testify on the needs of relative caregivers and their families, and work for changes in state and national policies that would assist such households (deToledo and Brown,

1995; Dunn, 2001; Roe and Minkler, 1998). The NCOG, for example, currently is advocating for laws that would support long term informal caregivers by increasing their access to medical benefits for the children in their care, educational affidavits and other needed provisions (Dunn, 2001). The passage of a resolution supporting increased assistance to older relatives raising grandchildren at the 1995 White House Conference on Aging; Congress' mandating of data collection on grandparent caregiving as part of the 2000 census; and legislative victories in a number of states all are indicative of the growing visibility and political organization of grandparent headed families and their allies.

NATIONAL RESOURCES

Although a number of public and private national programs and organizations provide assistance to those concerned about relative caregivers and their families, several are particularly worthy of mention for the help they may provide members of the aging network. These are:

AARP's Grandparent Information Center

Founded in 1993 with the aid of a grant from the Brookdale Foundation Group, the AARP's Grandparent Information Center (GIC) maintains a computerized database of some 800 support groups and other resources for relative caregivers in all 50 states. The Center receives 2,500 calls and letters annually from professionals as well as grandparent caregivers facing a range of social, legal, financial, medical, educational, and emotional challenges. (Goyer, 2001). Referrals are made in both English and Spanish, annual needs assessments conducted, and efforts made through focus groups and the like to document the concerns of grandparents from underserved communities. The Center's newsletter, published three times annually, is distributed to approximately 18,000 individuals and organizations. Center activities also include efforts to gather data, provide testimony, and educate caregivers, service providers, policy makers and the mass media about issues such as welfare reform as they effect grandparent caregivers and their families.

Generations United

Since its founding in 1986, Generations United has been unique in being the only national membership organization whose agenda is exclusively focused on intergenerational issues, strategies and policy advocacy (Generations United, 1998). Comprised of over 100 national organizations, as well as many state and local coalitions and individual supports, Generations United has become a key player in the area of relative caregiving, and a major spokesperson and advocate on policy issues affecting grandparent caregivers and their families (Butts, 2000). The organization's Grandparents and Other Relatives Raising Children Project convened an expert working group in 1997 which culminated in the publication of an intergenerational action agenda on relative caregivers and their families (GU, 1998). Based in part on the former, Generations United then developed its Public Policy Agenda for the 107th Congress (GU, 2001), making the case for legislation to address the special needs of relative caregivers and their households in the areas of legal rights and custody issues; financial support; and housing access. The organization currently is working with members of Congress to introduce supportive legislation that would better address the housing needs of relative caregivers and their families.

Finally, it was Generations United that successfully lobbied Congress to include older relative caregivers in the NFCSP. Toward the end of fostering Program implementation in this regard, Generations United has written A Guide to the National Family Caregiver Support Program and its Inclusion of Grandparents and other Relatives Raising Children (Beltran, 2001). This comprehensive and easy-to-use guide offers considerable background information on relative headed households, as well as on the NFCSP as it relates to this population. It further provides descriptive and contact information on a number of exemplary programs currently offered or being developed through the aging network in different parts of the country to help meet the needs of older relative caregivers and their families (see Appendix).

The Brookdale Foundation Group's Relatives as Second Parents (RAPP) Program.

The New York City-based Brookdale Foundation Group has been a leading force in grandparent and relative caregiving since the early 1990's, supporting the first national effort to identify and promote the replication of supportive interventions for grandparent

caregivers (Minkler et. al, 1993), and providing initial funds for AARP's Grandparent Information Center.

Since 1996, the Foundation's RAPP program has been awarding seed grants to community and state agencies to promote the creation or expansion of services for grandparents and other relatives who have become surrogate parents. By early 2001, 84 local programs and 27 state agencies were participating in the RAPP Network, and providing services to relative caregivers and their families in 37 states (Brookdale Foundation Group, 2001). Through an annual National Training Conference, a newsletter, and other technical assistance activities the Program provides participants with considerably more than the seed grants of \$10,000 over two years which are competitively awarded to support new programs or enable the expanding of existing services. Further, the Foundation's requirement that grant recipients transcend the boundaries of the traditional aging network and work collaboratively with other state agencies and local communities has led to numerous creative partnerships, as well as new funding streams and opportunities for service institutionalization.

Other national resources

Several other organizations listed in the Appendix also are important national resources in the area of relative caregivers and their families. The *Grandparent Caregiver Law* at the Brookdale Center on Aging at Hunter College thus provides legal information to caregivers and professionals alike, and conducts policy analysis on topics of direct relevance to kinship care. The Washington DC based *Child Welfare League of America* (CWLA) partners in the conducting of innovative research and demonstration activities in the area of kinship care, holds an annual kinship care conference, and also provides consultation and training to kinship care programs around the nation. The *Children's Defense Fund* has increasingly become involved in research and advocacy efforts in this area, most recently developing a survey based report on the special needs of children raised by relatives and ways to improve their access to Medicaid and the new National Children's Health Insurance Program (CHIP). Finally, and particularly through its role in the implementation of the NFCSP, the *Administration on Aging* is itself an increasingly important resource for those concerned about intergenerational families

headed by older relatives (see Appendix for contact information on these and other resources).

SELECTED "BEST PRACTICES"

A number of AAAs and state units on aging have been in the forefront of recognizing the rapid growth of older relative caregiver households and developing programs to help address the unique needs of these families in their jurisdictions. In many cases, seed grants and technical assistance from the Brookdale Foundation Group's RAPP program have provided initial resources needed to create or expand these programs and services. Descriptions of each of more than 100 local and state level Brookdale-funded programs are available from the Foundation, and offer many excellent examples of the varied forms such interventions may take (Brookdale Foundation Group, 2001). As noted above, a number of additional exemplary programs also are described in A Guide to the National Family Caregiver Support Program and its Inclusion of Grandparents and other Relatives Raising Children published by Generations United (Beltran, 2001).

Although in most cases preceding the inception of the NFCSP, the programs established to date illustrate how AAAs, state units on aging and other entities can help meet the needs of older grandparent caregivers and their families under each of the five categories of support specified in the Program. Below are some "best practice" examples on both the local and state levels, under each of these broad support categories: information; assistance; counseling, support groups and training; respite care; and supplemental services. Although space precludes inclusion of many other excellent programs, those cited have been chosen to illustrate the range and diversity of models developed and collaborative partnerships created to support such models in different parts of the county. The reader is referred to both Generations United's A Guide to the NFCSP and its Inclusion of Grandparents...(Beltran, 2001) and to the collected one page descriptions of local and state programs in the 2001 RAPP National Network (Brookdale Foundation Group, 2001) for many other excellent program models and examples.

Information to caregivers about available services.

The state units on aging in several states have developed, published and disseminated comprehensive resource guides for relatives raising children. Typically using a simple question-and-answer format, the guides cover topics such as child care, education, custody and other legal issues and also include contact information for a range of programs and resources. Washington State's 44 page resource guide, Relatives as Parents: A Resource Guide for Relatives Raising Children in Washington State, was the result of a partnership with Casey Family Programs and the State's AARP. Additionally, and in collaboration with State's University Cooperative Extension Program, Washington's State Unit on Aging established a web site which includes a statewide database of support groups, legal services, links to other relevant resources and special events that may be of interest to relative caregivers and their families. Finally, the state maintains a RAPP resource library including videos, books and other material available to caregivers and professionals working with this population (Beltran, 2001).

Information about available services and help in understanding the legal maze confronting many relative caregivers also is a goal of the Grandparents Raising Grandchildren Program of the East Central Illinois AAA. In addition to helping to create 7 support groups in its service area, this AAA partnered with its Human Services Agencies Consortium and the Decatur Bar Association to produce a day long "Legal Seminar for Grandparents Raising Grandchildren." The ECIAA now is working with new support groups to replicate the seminar in other geographic areas (Brookdale Foundation Group, 2001).

Assistance to caregivers in gaining access to services

Several state units on aging have developed creative approaches to assisting grandparent caregivers in gaining access to needed programs and services for themselves and the children in their care. Ohio's Department of Aging (ODA) thus funded a kinship care "navigator" to help such caregivers in both negotiating the legal system and accessing needed benefits. The State hopes to eventually make this model available in all of its 88 counties. Ohio's creation of a toll free hot line for kinship caregivers, and

Kentucky's 800 number Senior Health Insurance Information Program (SHIP) hot line (Brookdale Foundation Group, 2001) represent another creative approach that state units on aging may wish to emulate.

Improving access to services also is a goal of the KinCare program established by the AAA in Big Stone Gap, in Southwest Virginia. Relative caregivers, who may self-refer or be connected to the program through Head Start or other local programs and social service agencies, participate in a comprehensive family assessment conducted by KinCare staff and are referred for appropriate services. The program also publishes a monthly newsletter and distributes children's books, toys and other gifts donated from the local AARP and other agencies (Beltran, 2001).

Individual counseling, organization of support groups, and training caregivers to assist them in making decisions and solving problems relating to their caregiving roles

As noted above, developing grandparent and other relative caregiver support groups has been the most common means through which the aging network has assisted such caregivers in their jurisdictions. In some cases, support groups are loosely linked chapters of larger organizations, such as the California based Grandparents as Parents (GAP) Inc. , while most are autonomous groups established and led by health or social service providers, or by grandparent caregivers themselves.

Aided by a seed grant from the Brookdale Foundation Group, and contracting with a statewide non profit family service agency, Children and Families First, the intergenerational program of Delaware's State Unit on Aging began the Family Circles education and support group program for relative caregivers in 1997. Operating six support groups throughout the state, the program provides an important model in part because of its success in collaborating to insure the sustainability of these groups. Children and Families First thus has been able to maintain support groups at several sites after the termination of state funding, while funding from the State Unit on Aging has enabled a local Head Start and the Latin American Community Center to offer support groups to the families they serve (Beltran, 2001).

Although grandparent caregiver support groups have been identified in all 50 states, many older relatives are prevented from attending because of barriers such as lack of transportation and child care. The support groups established by the Region IV AAA in Michigan are among a growing number that have tried to address these barriers, providing free on-site child care and reimbursement for transportation (Brookdale Foundation Group, 2001). For some AAA's, partnering with Head Start and other family and children's services programs have proven an effective means of addressing the need for child care in conjunction with support group meeting attendance.

Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities

Occasional respite from the demands of 24 hour caregiving has been found to be among the most desired services by grandparent caregivers. To date, however, relatively few programs exist which address the respite needs of relative caregivers. An important exception on the state level involves Oklahoma Respite Resource Network, which was created in part through the Aging Services Division of Oklahoma's Department of Human Services. For over a decade, the ORRN has provided respite to grandparents and other caregivers with low to moderate incomes. Caregivers have wide discretion in the choice of respite care providers (provided they are age 18 or older and not household members), and a Respite Guide for Families and Providers is made available to those wishing assistance in this regard. DHS payments are made directly to the respite care provider, and the State's eleven AAA's are funding partners, whose accounts are charged if an eligible grandparent in their service area participates in the voucher program. Oklahoma's NFCSP funds are being used to expand this program to reach more relative caregivers aged 60 and over, while other state funds continue to be used to assist younger caregivers in need of this service (Beltran, 2001).

On the local level, center-based respite is provided in Michigan's Macomb County Department of Senior Citizen Services with funding from both the county budget and a local community foundation. Monthly respite for grandparent caregivers, as well

as Easter vacation week and day and week summer camp respite, are provided through several local YMCAs. Finally, the Tarrant County AAA's Relatives as Parents Coalition in Fort Worth, Texas, has been able to provide scholarships for respite services through a partnership with a non profit that provides respite care for foster families (Brookdale Foundation Group, 2001).

Supplemental services on a limited basis, to complement the care provided by caregivers

The category of "supplemental services" delineated in the NFCSP is particularly broad, and as such can be utilized to provide a wide range of services needed by grandparent and other relative caregivers. Addressing the special mental health and educational needs of children in the care of grandparents and other relatives represents an area of considerable importance to caregivers, for example, and one that can be subsumed under "supplemental services." Southwest Washington's AAA offers therapeutic groups for children aged 5-8 and 9-12. Led by mental health professionals who employ play therapy and other techniques, the six week sessions have received positive evaluations and offer a promising model for work in this area (Beltran, 2001). Organized tutorial programs teaching social skills, written communication, and computer skills on donated computers are a key feature of the Grandparents as Parents program at Westcoast Children's Center in El Cerrito, CA., and are held concurrently with one of two grandparent support groups (Brookdale Foundation Group, 2001).

Supplemental services also may include attention to the special needs of particular racial/ethnic groups of relative caregiver families. Project GUIDE in Detroit, Michigan provided an important early example of "best practices" addressing the special emotional and other needs of African American relative caregivers and their families impacted by substance abuse. In addition to support groups, individual counseling and other assistance to caregivers, a self esteem group for preadolescent girls, tutoring, and family visits to the black rodeo and other cultural events were among the special activities provided (Roe and Minkler, 1998). More recently, Northwestern Washington has begun plans to use its NFCSP funds for a tribal kinship care program. The proposed program

would address the needs of relative caregivers and their families belonging to the six tribes in its area, including support groups, referral to attorneys familiar with tribal law, and outreach activities (Beltran, 2001).

Supplemental services support also may be used to nurture leadership among grandparent and other relative caregivers and their providers. The earlier mentioned East Central Illinois AAA thus has established a Grand Leaders Group comprised of support group leaders from across the region who meet quarterly, share experiences and identify barriers and problems confronting relative caregivers (Brookdale Foundation Group, 2001). Similarly, the Region IV AAA Senior Volunteer Program in St. Joseph, Michigan provides opportunities for caregivers to serve in its Senior Corp Foster Grandparent and Senior Companionship Program, both sharing their skills and supplementing their family incomes (Brookdale Foundation Group, 2001). When relative caregivers are provided such opportunities for service and/or receive special training and technical assistance, they not only profit as individuals but often improve their ability to contribute to the grandparent caregiving groups and communities of which they are a part.

Finally, and although many supplemental services may most logically be provided on the local level, statewide activities also should be considered. The statewide trainings and conferences on kinship care being offered in many states, often through collaborative partnerships between several public and private sector agencies, are among the types of activities which may be conducted under the umbrella of supplemental services.

SAMPLE COMPREHENSIVE PROGRAMS

The best practice examples above have been included to illustrate innovative programs or program components relating to each of the five categories of NFCSP support. In reality, however, the many often interrelated needs of older relative caregivers and their families underscore the importance of developing interventions that are comprehensive and multi-level in focus. Below are three outstanding examples of such comprehensive programs:

Edgewood Center's Kinship Support Program in Northern California

Arguably the oldest comprehensive program in the nation for relative caregiver families is the Northern California-based Kinship Support Network of the Edgewood Center for Children and Families. Serving as many as 225 families daily, the program is designed to fill any gaps in public social services to relative caregivers and their families. One-to-one peer mentoring, parenting education, support groups, case management, and family activities are among the services offered at its three locations in San Francisco and San Mateo Counties. Edgewood's Kinship Support Network has been designated as a model by the State legislature, which has also paid the Center to both write a detailed training manual and provide technical assistance and training to other programs around the state (Cohon, 2001).

The GrandCare Program for Grandparents and Other Relatives Raising Children in Charlotte, North Carolina

Many comprehensive programs for relative caregivers and their families begin with support groups and expand over time to fill a multiplicity of needs. The GrandCare Program of Charlotte-Mecklenburg Senior Centers Inc. provides an important example. Beginning with two support groups, the GrandCare Program, which received a seed grant from the Brookdale Foundation Group in 1997, has expanded to include case management, advocacy, education, and information and referral to relative caregivers regarding legal issues, housing, respite and other areas. GrandCare also provides educational workshops for school staffs, social service agencies, child care centers, and other providers working with this population. The development and use of an intake form for coordinating confidential collaboration with other professionals who assist GrandCare caregivers and their families also has been a major contribution of this program. Finally, GrandCare hosts an annual Public Forum and conference which brings together concerned professionals as a means of helping them share information on national and state policy developments, promising replication programs and other matters (Brookdale Foundation Group, 2001).

GrandFamilies House in Boston, MA.

Among the most exciting new comprehensive approaches to meeting the needs of relative caregivers and their families is Boston's GrandFamilies House, a 26 unit complex of two, three and four bedroom apartments built expressly to accommodate the needs of relative caregivers and their families. GrandFamilies House was developed by two local non profits, Boston Aging Concern's Young and Old United, Inc. (BAC-YOU) and the Women's Institute for Housing and Economic development. Obtaining 100 section 8 vouchers and federal "HOME" housing program funds, these organizations were able to combine public and private financing to create the complex. Physical accommodations to aid both toddlers and seniors, on site programs, and a task force to promote advocacy on behalf of grandparent headed households are among the features offered (Kauffman and Goldberg-Glen, 2000).

Currently, replications of GrandFamilies House are getting underway in eight other locations: Baltimore, Buffalo, Chicago, Nashville, New Jersey, New York City, Ohio, and Philadelphia, and Generations United is closely tracking their progress. In addition to adapting a promising program model, these replication projects are offering important new lessons of their own. The garnering of substantial local and community support in Baltimore thus has led to the City's agreeing to exempt this project from a moratorium on new senior housing construction. Although far more broad ranging policy changes are needed to meet the housing needs of relative caregivers and their families (see above) interventions like GrandFamilies House provide an important example of local level programs that can make a difference. Area Agencies on Aging may wish to consider how they can collaborate with or help to begin a GrandFamilies replication project in their geographic area in part with the support of NFCSP funds.

IMPLICATIONS FOR THE AGING NETWORK

As the preceding section has illustrated, both AAAs and state units on aging often have been in the forefront of developing creative programs to address the needs of older grandparent caregivers and their families. From their experiences and those of health and social service providers; through a rapidly burgeoning research base; and through the voices of grandparent caregivers and their families, a number of implications for practice

can be drawn. State units on aging and AAAs concerned with developing or expanding programs designed to help meet the needs of grandparent caregivers and their families thus may want to consider the following principles:

- ***“Start where the people are” before deciding on a new program or activity.***

Grandparent caregivers are articulate spokespersons for their own needs and concerns and those of their families and fellow caregivers. New programs that begin with their agenda, rather than that of a funder or provider, are far more likely to achieve success. Relative caregiver town halls and forums, surveys and focus groups and other methods should be employed to help determine the particular needs of grandparent caregivers in a given geographic area. Additionally, however, both AARP’s Grandparent Information Center and Generations United have conducted surveys involving hundreds of relative caregivers around the nation. Documents like Generations United’s Grandparents and Other Relatives raising children: Grassroots concerns and solutions form across the United States (2001), may provide much useful information in this regard.

- ***Identify and address the special cultural, linguistic and other needs and concerns of diverse groups of relative caregivers.*** As noted earlier, although grandparent caregiving cuts across class and racial/ethnic group lines, it is particularly prevalent among African American families and also appears more common among Hispanics and some other communities of color. Special attention is needed to the meaning and forms of relative caregiving in diverse communities, so that programs can be developed that are tailored to the specific needs and strengths of different population groups. Working through appropriate cultural institutions in these diverse communities; providing bilingual services, including support groups and newsletters; and holding special cultural pride events for relative caregiver families of different racial/ethnic groups all may be important means of adhering to this principle.
- ***Search out and develop creative partnerships.*** As indicated above, a major factor responsible for the success of the Brookdale Foundation Group's RAPP Program may well lie in its insistence that funded entities work collaboratively with other agencies

and organizations, including those outside the aging network. By partnering with voluntary children and youth organizations; faith based entities; public sector programs such as Head Start and Section 8 Housing; and local hospitals and schools, AAAs and state units on aging can vastly increase the resource base, visibility and effectiveness of their NFCSP efforts. Partnering with agencies or programs which are not limited in terms of client age further may enable the programs developed to better meet the needs of the many relative caregivers who are below age 60.

- ***Think broadly and creatively.*** As noted above, the language outlining the NFCSP was intentionally broad and non specific, to enable members of the aging network to draw on local knowledge of needs and opportunities to make the best possible use of the funds provided. Particularly when considering supplemental services that may benefit older relative caregivers and their families, taking advantage of the non specific language of the Program guidelines should enable aging network members considerable degrees of freedom in best meeting the needs of the relative caregiver populations they serve.

- ***Recognize and build on the strengths of grandparent and other relative caregivers*** Although this monograph has necessarily focused on the needs of older relative caregivers, such individuals often demonstrate immense strengths in coping with the daunting challenges of “second time around” parenting and contributing to their communities. By providing opportunities for relative caregivers to participate in special trainings and leadership activities; become support group leaders or co-facilitators; or serve as spokespersons with the mass media, policy makers etc., members of the aging network can build on these strengths while simultaneously building the self esteem of older caregivers.

- ***Maintain open communication with organizations that can advocate for policy change.*** As noted above, achieving substantive improvements in the well being of relative caregivers and their families frequently requires new legislative and policy changes, framed in an intergenerational context, that support, rather than penalize these families (Butts, 2000). Although AAAs and state units on aging generally

cannot advocate directly for legislative changes, they are in an excellent position to help document the need for new policy directions. By providing such documentation, including, for example, stories of grandparents adversely affected by existing housing or welfare policies, and those who have benefited from new programs and services, members of the aging network can help create the knowledge base vital to organizations like AARP, Generations United, the Child Welfare League of America, and the Children's Defense Fund as they work to promote needed policy change.

The wonderful opportunity provided by the NFCSP to develop and expand innovative and supportive programs for relative caregivers and their families must not overshadow the need for coherent public and private sector policies that support the growing number of intergenerational families headed by grandparents and other relatives.

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AARP Grandparent Information Center

601 E Street, NW
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Relatives as Parents Program (RAPP)

Brookdale Foundation Group
125 East 56th Street
New York, NY 10022
(212) 308-7355
www.ewol.com/brookdale

Generations United

122 C Street, NW, Suite 820
Washington, DC 20001
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Administration on Aging

330 Independence Avenue, SW
Washington, DC 20201
(202) 619-7501 (National Aging Information Center)
(800) 677-1116 (Eldercare Locator)
www.aoa.gov

Grandparent Caregiver Law Center

Brookdale Center on Aging
1114 Avenue of the Americas
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(646) 366-1000
www.brookdale.org

Child Welfare League of America

440 First Street, NW, Third Floor

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(202) 638-2952

www.cwla.org**Children's Defense Fund**

25 E Street, NW

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(202) 628-8787

www.childrensdefense.org**American Bar Association Center on Children and the Law/ Commission on Legal Problems of the Elderly**740 15th Street, NW, Washington, DC 20005(202) 662-1000 www.abanet.org**Legal Services for Prisoners with Children**

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Kentucky KinCare Project

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MASS.

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 Boston Aging Concerns-Young and Old United (BAC-YOU)
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 67 Newbury Street
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MICHIGAN

Senior Volunteer Programs
 Region IV AAA of Southwest Michigan
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NORTH CAROLINA

GrandCare Program
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 Sue M. Korenstein, GrandCare Director
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OHIO

Grandparents Raising Grandchildren
 Ohio Department of Aging
 Charles Wilson, RAPP Coordinator
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OKLAHOMA

Oklahoma Respite Resource Network
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TEXAS

Relatives As Parents Coalition
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VIRGINIA

KinCare
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WASHINGTON

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